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Thalassaemia : A study on the perception of patients and family members (Article)

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Abstract

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Marked improvement in the management of thalassaemia has not been matched by progress in psychosocial rehabilitation as thalassaemia continues to pose challenges to patients and their family members. Few studies have been carried out in Malaysia to look at such issues. This study is therefore to explore the concerns, beliefs and feelings about thalassaemia. It was conducted in the year 2009 over 7 months on "focus groups", in patients aged 8-22 years and parents attending Paediatric Clinic of Tengku Ampuan Afzan Hospital, Kuantan, Pahang. Results showed that concerns and adverse impact were related to lower grades in education, poor self-image, less chance of employment, marriage, financial burden and social integration. Compliance to subcutaneous iron chelator was poor. There were various concerns related to blood transfusion therapy. It is evident that thalassaemia greatly affects the psychosocial dimensions and a more structured long term psychosocial support is needed to improve quality of life of patients.

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Families Patients Perception Thalassaemia

Indexed keywords

EMTREE drug terms: deferasirox deferiprone iron chelating agent

EMTREE medical terms: adolescent adult alternative medicine article blood transfusion body image child clinical article drug eruption educational status employment female growth disorder health belief human income injection site pain integration male marriage parent patient compliance school child self concept self esteem short stature social psychology thalassemia

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